

The Epidemiology of Cancer and the Delivery of Medical Care Services

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The paper is based on his presentation at the Second Binational Symposium: United States-Israel, held October 17-19, 1983, in Bethesda, Md.

Synopsis

Data collected primarily for epidemiologic purposes can be used to address questions concerning medical care for cancer in the United States. This was done directly for the period 1969-71 through an interview survey of a sample of cancer patients identified in the Third National Cancer Survey to obtain information on length of hospital stay, cost of care, source of payment,

and related issues. Since that time the Surveillance, Epidemiology, and End Results (SEER) Program was established by the National Cancer Institute to measure cancer incidence and cancer patient survival in 10 percent of the U.S. population on a continuing basis.

Using the SEER data and those from the earlier cancer surveys, evidence is presented for the increasing need for medical care resources for some of the major cancers, such as cancers of the lung and prostate. Data from the National Hospital Discharge Survey for 1979 reveal an average length of stay of 12.3 days for each hospital discharge with a diagnosis of cancer, ranging from 8.5 days for those with cancer of the cervix uteri to 20 days for those with brain cancer. Some suggestions are made for applying hospital data on length of stay from the National Hospital Discharge Survey to estimates of cancer incidence from the SEER Program to obtain estimates of numbers of hospital days required during the first period of hospitalization for cancer. This estimate for the United States for 1983 was almost 11 million hospital days for all cancers combined.

EPIDEMIOLOGY IS PRIMARILY concerned with the study of determinants of disease frequency in populations. The three measures of disease frequency usually employed are incidence—the number of new cases of the disease occurring in the population during a year, prevalence—the number of cases of the disease active in the population as of a point in time or during a period of time, such as a year, and mortality—the number of persons dying of the disease during a year. The measurement of cancer incidence and mortality is more readily and more accurately accomplished than for most chronic diseases. Measurement of cancer prevalence, on the other hand, is much more difficult. The major problem is the difficulty in characterizing individuals who have had the disease as being free of it at any specific time following the initial diagnosis. Some population-based cancer registries that carry out continuous followup of patients from date of diagnosis until date of death have attempted to obtain an indication of disease status at the time of each followup determination, but this has not been very successful.

This difficulty is unfortunate because prevalence is perhaps the most relevant measure of disease frequency for dealing with issues of medical care resources; presumably those with active disease are the persons in need of medical care. Those who first develop the disease during the year or those who die of the disease during the year represent only part of the total number needing

medical care. Many in need of medical care during the year are survivors of cancers diagnosed in earlier years but whose disease is still active or has recurred. The American Cancer Society estimates that this year there are some 5 million persons in the population who have ever had cancer and that some 3 million of them were diagnosed 5 or more years ago (1). Even if these estimates are accurate, this does not mean that the remaining 2 million persons have active disease and are in need of medical care or that all of the 3 million 5-or-more-year survivors are disease free and no longer in need of care.

Even though we have not been successful in measuring the prevalence of cancer in the U.S. population, we can learn much about the current and potential demands on the medical care system by studying data on persons newly diagnosed as having cancer during defined periods. One of the more comprehensive studies attempting to do this was that by Scotto and Chiaze on the cost of hospitalization for cancer (2). The authors obtained detailed information about hospitalization and payments to hospitals during the first 2 years following diagnosis from a sample of persons included in the Third National Cancer Survey (TNCS). The TNCS was conducted by the National Cancer Institute and covered seven large metropolitan areas and two entire States (3). It attempted to identify every case of cancer first diagnosed during the period 1969 through 1971 in these areas, about 10 per-

cent of the U.S. population. By analyzing the characteristics of patients included in their sample, the characteristics of their cancers, and their hospital utilization, Scotto and Chiazzo were able to identify a number of factors that influenced hospital use. These included age of patient, length of survival following diagnosis, specific cancer site, and extent of disease at the time of diagnosis.

I know of no more recent large-scale studies specifically designed to measure the medical care aspects of cancer since this study. Following the Third National Cancer Survey, however, the National Cancer Institute established the Surveillance, Epidemiology, and End Results (SEER) Program in 1973 to provide cancer incidence and cancer patient survival data on a large segment of the U.S. population on a continuing basis (4). While the program was established to serve primarily as a basis for epidemiologic research, it has also provided a basis for monitoring the management of cancer in the United States over time. The purposes of this paper, therefore, are to examine data from the SEER Program, those from earlier cancer surveys, and national data on cancer mortality, hospitalization, and physicians' office visits; and to discuss the implications of these data for the medical care system in the United States.

Data Sources

Several national data resources are available that bear on this problem. They can be described briefly as follows:

The SEER Program. This Program, established by the National Cancer Institute in 1973, now consists of 10 population-based cancer registries covering about 10 percent of the United States population. The details of the program are described elsewhere (4).

The national cancer surveys. Over the years the National Cancer Institute has conducted three large cancer incidence surveys in the United States—the first in 1937, the second in 1947, and the third in 1969–71—each covering about 10 percent of the U.S. population (3,5,6). In addition to these, a special cancer incidence survey was carried out in the entire State of Iowa in 1950 (7), and Connecticut has had a continuous statewide cancer registry since 1935 (8). Both of these States are currently members of the SEER Program. In the following discussion of cancer incidence trends, data for five SEER areas are used for which data are also available for the time periods around the Second and Third National Cancer Surveys. These include Atlanta, Detroit, Connecticut, Iowa, and San Francisco. The issues of comparability of these data over time have been discussed elsewhere (9).

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Cancer patient survival data. Prior to the establishment of the SEER Program, the National Cancer Institute obtained cancer patient survival data by sponsoring the End Results Program, a set of primarily hospital-based cancer registries (10). For four registries—the entire State of Connecticut, a large number of hospitals in California, Charity Hospital in New Orleans, and the University of Iowa Hospital—survival data are available for patients diagnosed from 1950 through 1973 with followup through 1978. This makes it possible to analyze changes in survival rates over time, but problems of comparability of these data with those from the SEER Program remain.

Mortality, hospitalization, and physicians' office visits. The mortality data used in this report were derived from those collected for the entire United States by the National Center for Health Statistics (NCHS). Copies of computer tapes containing data on all cancer deaths from 1950 through 1979 have been obtained from the NCHS. Information on length of hospital stay by patient characteristics, including diagnosis, is based on those published by the Center's National Hospital Discharge Survey (NHDS) (11). This survey is based on a probability sample of discharges from all noninstitutional hospitals in the United States exclusive of military and Veterans Administration hospitals. Data on numbers of visits to physicians' offices for persons diagnosed as having cancer were obtained from those produced by the National Ambulatory Medical Care Survey (NAMCS) of the NCHS (11). This survey uses a probability sample of physicians' office practice in the United States.

Results

Data generated by these resources raise questions about the use of the medical care system for the management of cancer. Some of these are illustrated in the following sections.

'The cancers for which incidence rates are increasing will place increasing demands on the medical care system. Where mortality rates are also increasing, even greater volume of hospitalization is required.'

mortality from the disease. Mortality rates, however, are influenced not only by medical care but also by the incidence of the disease in populations. One way of illustrating this is to show trends in incidence and mortality side by side for specific cancers so that one can draw some inferences from their patterns. Figure 1 shows the trend in lung cancer incidence and mortality for white males from approximately 1950 to 1978-79. Both have been increasing and are beginning to show some signs of leveling off. There is also some evidence of an increasing gap between incidence and mortality, which suggests that the increasing mortality has resulted from increasing incidence, but there is also some suggestion that survival among those diagnosed with lung cancer may have improved slightly. Figure 2 shows the incidence and mortality trends for stomach cancer among white males. It shows a pattern of decreasing rates for both incidence and mortality that are approximately parallel. Thus one would conclude that the decreasing mortality is primarily due to a consistent decrease in incidence and not to improved medical care. Figure 3 shows the corresponding trends for cancer of the colon and rectum combined for white males. Here the mortality rates show a very slightly decreasing trend while the incidence rates show an increasing trend. This suggests that, while the incidence rates have increased, survival among those diagnosed with the disease has probably improved. Figure 4 shows a similar picture for cancer of the prostate for white males—increasing incidence and virtually level mortality. Again, one might conclude that this is evidence of improving survival.

Extent of the problem. The American Cancer Society estimates that there were 895,000 new cases of cancer and 440,000 cancer deaths in 1983 (1). The estimate of new cases was obtained by applying the 1973-79 SEER incidence rates to the Census Bureau projection of the U.S. population for 1983 and the estimated number of deaths by applying the 1973-78 U.S. cancer mortality rates to that population. The distributions of these estimates according to some of the major cancer anatomical sites are shown in table 1. Three sites—colon and rectum combined, lung, and breast—account for almost half the new cases and almost half the deaths. The median age at diagnosis and at death is also shown for each cancer site in table 1. It can be seen that half of the cancer cases occur among persons aged 65 or older. Half of the prostate cancers occur in those over age 73, while the median age at diagnosis for Hodgkins disease is only 34.

Cancer trends. One of the possible goals of the medical care system as applied to cancer is to reduce the

Table 1. Estimated number of new cancer cases, estimated number of cancer deaths, and median age at diagnosis and at death, United States, 1983

Primary cancer site	New cases		Deaths	
	Estimated number ¹	Median age ²	Number ³	Median age ²
Stomach.....	24,500	70.2	13,900	71.5
Colon.....	87,000	70.5	49,600	71.8
Rectum.....	39,000	68.4	8,500	71.5
Pancreas.....	25,000	69.2	22,600	69.5
Lung.....	135,000	64.8	117,000	65.7
Female breast.....	114,000	60.3	37,200	63.2
Cervix uteri.....	16,000	52.7	7,000	61.8
Corpus uteri.....	39,000	60.9	3,000	69.5
Ovary.....	18,200	60.0	11,500	64.2
Prostate.....	75,000	73.1	24,100	76.5
Urinary bladder.....	38,500	69.4	10,700	74.4
Kidney.....	18,200	63.9	8,500	66.2
Brain.....	12,600	54.9	10,800	58.8
Hodgkins disease.....	7,100	34.0	1,600	53.6
Non-Hodgkins lymphoma.....	23,600	63.9	12,300	67.0
Leukemia.....	23,900	65.8	16,100	67.1
Total.....	855,000	65.4	440,000	67.9

¹ Based on SEER incidence rates for 1973-79.

² Based on new SEER data for 1973-77.

³ Based on U.S. death rates for 1973-78.

SOURCE: References 1 and 4.

Figure 1. Age-adjusted (1970 U.S. standard) lung cancer incidence rates per 100,000 population, five geographic areas (5 GA) combined and age-adjusted mortality rates, 5 GA and total United States, white males, 1947-78

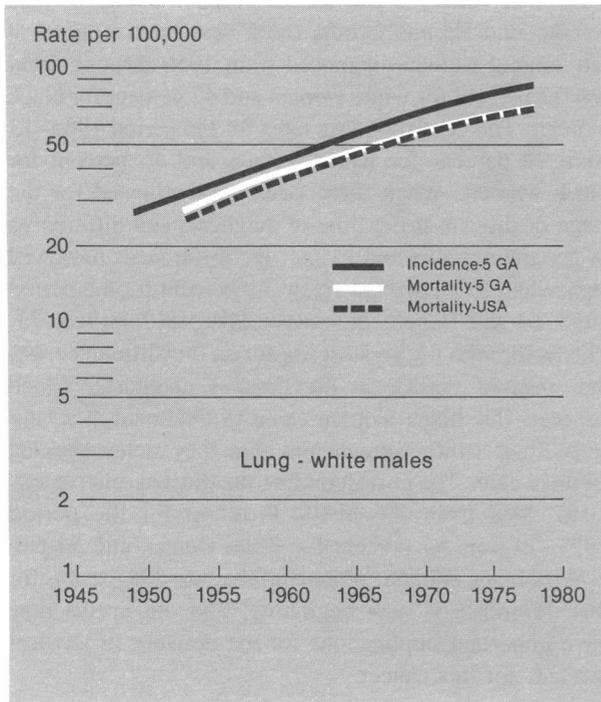


Figure 2. Age-adjusted (1970 U.S. standard) stomach cancer incidence rates per 100,000 population, five geographic areas (5 GA) combined and age-adjusted mortality rates, 5 GA and total United States, white males, 1947-78

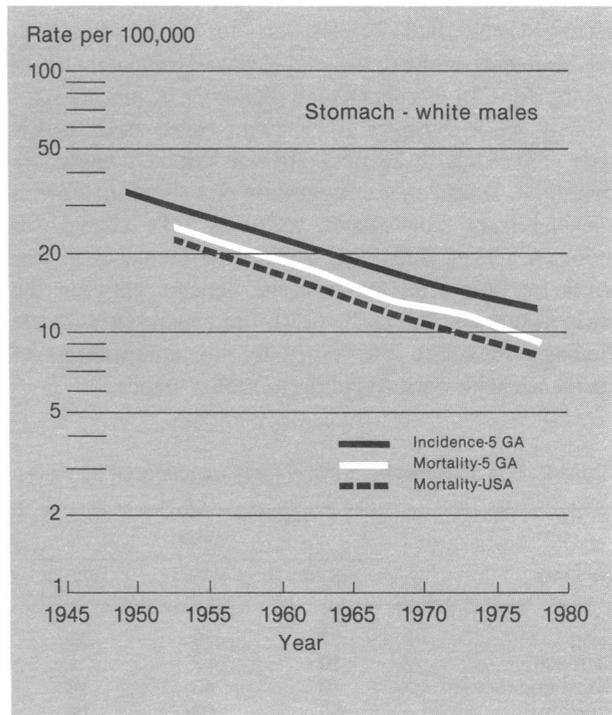


Figure 3. Age-adjusted (1970 U.S. standard) colon and rectum cancer incidence rates per 100,000 population, five geographic areas (5 GA) combined and age-adjusted mortality rates, 5 GA and total United States, white males, 1947-78

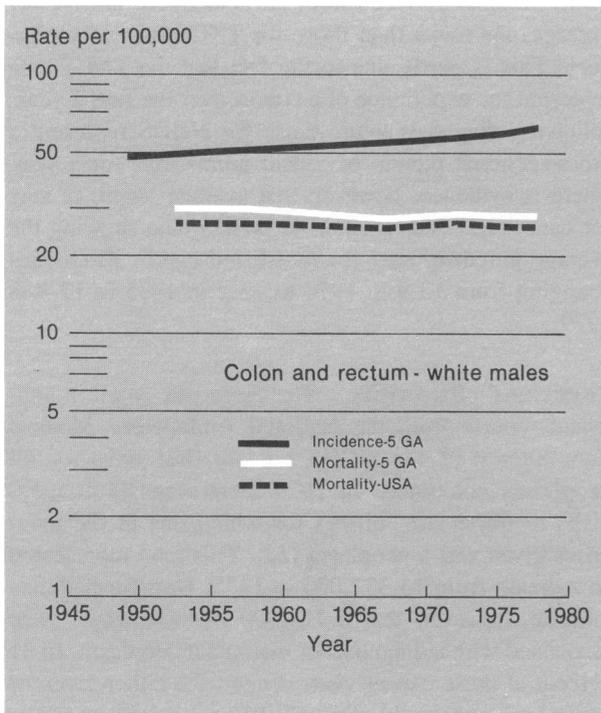
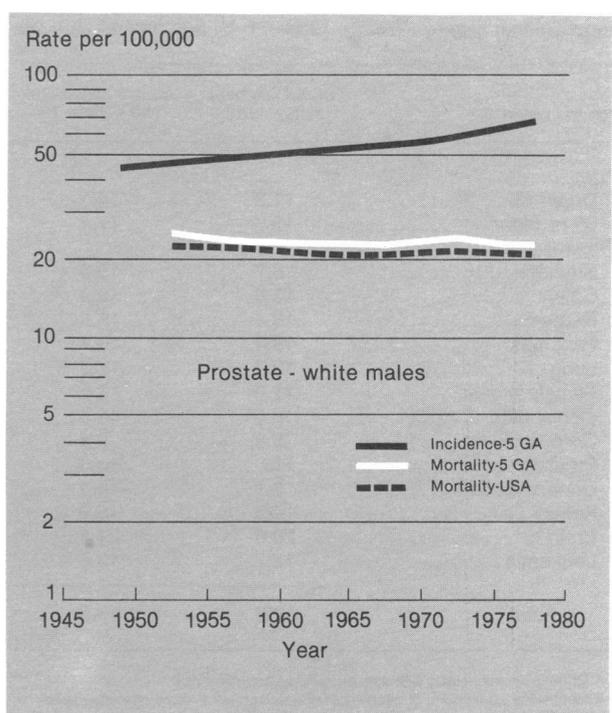


Figure 4. Age-adjusted (1970 U.S. standard) prostate cancer incidence rates per 100,000 population, five geographic areas (5 GA) combined and age-adjusted mortality rates, 5 GA and total United States, white males, 1947-78



Survival rates. For a more direct examination of changes in survival rates, table 2 shows the 5-year relative survival rates for the four cancers mentioned previously for white males for the periods 1960-63, 1970-73, and 1973-79. The rates for the first two periods were derived from the End Results Group data based on the four large cancer registries (12) mentioned previously, while those for 1973-79 are based on the SEER data (13). Thus these rates are not strictly comparable over time. However, the suggestion of a slight increase in survival from lung cancer, relatively little change for stomach cancer, and fairly substantial increases in survival for colorectal and prostate cancers between the early 1960s and the early 1970s are consistent with the findings suggested previously by the comparisons of incidence with corresponding mortality trends.

Table 2. Five-year relative survival rates (percent), white males

Cancer site	Period		
	1960-63	1970-73	1973-79
Lung	7	9	10
Stomach.....	10	12	12
Colon and rectum.....	40	46	46
Prostate	50	63	64

SOURCE: End Results Group and SEER.

Table 3. Average length of stay (days) among cancer patients discharged, National Hospital Discharge Survey 1979, compared with length of stay among cancer patient admissions, Third National Cancer Survey (TNCS), 1969-71, by age and primary site

Age and cancer site	Hospital Discharge Survey, 1979 ¹	Hospital admissions, TNCS, 1969-71 ²
Age:		
Under 65	11.3	14.1
65 or older	13.3	17.4
Primary site:		
Stomach.....	15.7	19.9
Colon	15.8	19.9
Rectum.....	16.4	19.9
Pancreas	18.0	19.4
Lung	12.7	17.2
Female breast.....	11.0	13.5
Cervix uteri	8.5	11.9
Corpus uteri.....	9.3	9.9
Prostate	11.0	15.0
Urinary bladder.....	9.1	10.4
Kidney	14.2	16.9
Brain	20.0	21.1
Leukemia.....	12.7	13.8
Total	12.3	15.6

¹ All hospital discharges with cancer as first-listed diagnosis.

² All hospital admissions of cancer patients during first 2 years after diagnosis.

SOURCE: References 2 and 14.

There are also striking differences in survival between black and white cancer patients. This can perhaps best be illustrated by examining the survival rates following diagnosis of cancer of the uterine corpus. Using the data for the End Results Group, the 5-year relative survival rate among women diagnosed from 1950 through 1964 was 73 percent for white women and 42 percent for black women. The corresponding rates for the period 1965-73 were 79 percent for white women and 46 percent for black women. When these rates were adjusted for the stage of disease at the time of diagnosis and differences in geographic area and in age, the differences narrowed somewhat, to 70 percent versus 49 percent for the period 1950-64 and 76 percent versus 62 percent for 1965-73. The factor with the greatest impact on this difference was the stage of disease at the time of diagnosis, which suggests that black women came to treatment at a later stage than white women and that they delay seeking medical care. The corresponding unadjusted relative survival rates from the SEER Program for the period 1973-79 were 87 percent for white women and 54 percent for black women. A study of the possible reasons for this difference is now beginning, and the results may have important implications for the delivery of medical services for this cancer.

Length of hospital stay. The average length of hospital stay for all hospital discharges with cancer as the first-listed diagnosis, based on the National Hospital Discharge Survey for 1979, is given in table 3 (14). Corresponding figures for average length of stay from the Third National Cancer Survey are also given. The NHDS averages are lower than those for TNCS for every category. This is partly due to the fact that the TNCS data represent the experience of a cohort over the first 2 years following diagnosis while those for NHDS represent a cross-sectional picture of cancer admissions for a year. There is evidence, however, that average length of stay for cancer has decreased, with NHDS data showing the average length of stay for first-listed cancer discharges changing from 13.9 in 1970 to 13.2 in 1975 to 12.3 in 1979.

Physicians' office visits. The diagnostic detail in published reports from the National Ambulatory Medical Care Survey of the NCHS contain data only for all neoplasms combined. In 1979 there were 14,205,000 visits to physicians' offices for which one of the diagnoses given was a neoplasm (15). This total represented an increase from 13,332,000 in 1975. Unpublished data indicate, however, that 8,913,000 of these visits were associated with a diagnosis of malignant neoplasm. In 31 percent of these cancer visits drugs were either given or prescribed and in 13 percent office surgery was per-

formed. Data were not readily available to indicate what proportion of the visits involving drugs represented chemotherapy for cancer.

Discussion

I have shown how data collected primarily for purposes of epidemiologic study might be used to raise some medical care issues for those who develop cancer. The cancers for which incidence rates are increasing will place increasing demands on the medical care system. Where mortality rates are also increasing, even greater volume of hospitalization is required. Data from Medicare, for example, show that among those who were hospitalized for and died of cancer, the average number of days of hospitalization in the last year of life was 38, higher than that for any other major cause of death category ("Use and Cost of Medicare Services in the Last Days of Life" by J. Lubitz, R. Prihoda, and W. Everhart, Health Care Financing Administration, Washington, D.C., 1982, unpublished paper). Thus high or increasing mortality rates also point toward cancers where increased efforts at earlier detection are indicated. A larger number of certain cancers can be expected in geographic areas with large populations of specific ethnic groups. When a particular ethnic group has an abnormally low survival rate for specific kinds of cancer, efforts should be made to determine whether changes in medical care delivery can improve the situation.

Independent of these epidemiologic data, other data systems measure certain aspects of medical care in the United States. To the extent that diagnostic information is

available, these other data systems can shed some light on the delivery of medical care services for cancer. The fact that these systems exist side by side can be useful for the policymaker. The epidemiologic data can be used to predict the extent of demand on the medical care system, to indicate the size of the groups affected by specific proposed changes in the medical care system and, possibly, to evaluate the impact of such changes over time. The medical care data systems, on the other hand, provide quantification of services delivered and resources used.

Data from these various systems might be put together in a number of ways to arrive at estimates that have implications for the medical care system. In table 4 the average length of stay among patients discharged with first-listed cancer diagnoses for 1979, by primary site, was used, and the assumption was made that this would be equivalent to the length of the first period of hospitalization of newly diagnosed cancer patients. These averages were multiplied by the corresponding projected numbers of new cancer cases for 1983 to obtain expected numbers of days during the first period of hospitalization among these patients. As another example, we could assume that the SEER survival rates for patients diagnosed in 1973-79 applied to the 855,000 projected new cases in 1983. Among these, there would then be 299,250 deaths in the first year following diagnosis. If the estimates for 1976 from the Medicare data applied—that hospitalized cancer patients who died used 38 days of hospitalization in their last year of life—this group alone would require over 11.3 million hospital days in their last year of life. The assumptions made in these

Table 4. Expected number of hospital days during first period of hospitalization for estimated number of new cancer cases in 1983

Cancer site	Estimated number of new cases, 1983 ¹ 1	Estimated average days of hospital stay ² 2	Estimated number of hospital days during first hospitalization 3 = 1 × 2
Stomach.....	24,500	15.7	384,650
Colon.....	87,000	15.8	1,374,600
Rectum.....	39,000	16.4	639,600
Pancreas.....	25,000	18.0	450,000
Lung.....	135,000	12.7	1,714,500
Female breast.....	114,000	11.0	1,254,000
Cervix uteri.....	16,000	8.5	136,000
Corpus uteri.....	39,000	9.3	362,700
Ovary.....	18,200	11.8	214,760
Prostate.....	75,000	11.0	825,000
Urinary bladder.....	38,500	9.1	350,350
Kidney.....	18,200	14.2	258,440
Brain.....	12,600	20.0	252,000
Leukemia.....	23,900	12.7	303,530
Total.....	855,000	12.3	10,516,500

¹ American Cancer Society estimates based on SEER incidence rates for 1973-79 and U.S. Bureau of the Census population projections for 1983.

² National Hospital Discharge Survey estimates for first-listed diagnoses of hospital discharges with cancer at specific sites.

examples are oversimplified, and a number of refinements could be made. But often for planning or evaluation purposes only gross estimates are required.

Among the various sources of data presented here, the SEER Program undoubtedly produces the most accurate cancer data because it is specifically oriented toward both the epidemiologic and the clinical aspects of cancer. Not only are data obtained primarily from hospitals by trained abstractors, but they are subject to a comprehensive, systematic set of quality control procedures. The coding by the National Center of Health Statistics of cancer by specific anatomic site as the underlying cause of death is remarkably accurate, as indicated by studies assessing accuracy of cancer designation on death certificates (16). The few sites for which problems of accuracy exist are fairly well known, and the extent of the error can be at least roughly estimated. A study carried out by the Institute of Medicine, National Academy of Sciences, of the reliability of data collected by the NHDS revealed that the accuracy of specific cancer diagnoses in the survey was less than 60 percent, primarily because of inadequacy of information on the face sheets of medical records (17).

Less is known about the accuracy of information on physicians' office visits collected in the National Ambulatory Medical Care Survey. Since a maximum of three diagnoses per visit was coded, it is likely that cancer appeared as one of the three if the visit concerned the patient's cancer. The accuracy of the recording of the specific information and of the corresponding coding is not known.

Since reporting of nonmelanoma skin cancers is not included in the SEER Program, it is assumed that almost all the remaining cancer cases in an area will be identified by obtaining information from hospitals. Therefore, data on persons seen in physicians' offices have not been considered necessary for measurement of cancer incidence. They have been used increasingly in recent years, however, to provide a more complete picture of the first and subsequent courses of treatment, because it is thought that more chemotherapy is now given in physicians' offices than in the past. Thus, to understand better the role of the physician's office in the treatment of cancer, more work needs to be done in analyzing data already being collected by the NAMCS. Also, samples of physicians' office practice records might be drawn in areas where population-based cancer registries exist to identify the medical care patterns for cancer more directly.

The foregoing discussion has attempted to illustrate the use of epidemiologic data to identify groups at risk of using greater amounts of medical care resources, with greater emphasis on hospitalization. Except for the data on trends in cancer incidence and mortality, most of the

data presented pertained to a particular period of time. As the SEER Program matures further, it will be increasingly possible to determine changes in such measures as the incidence of short-term survivors from specific cancers, for example, a group that is a heavy consumer of hospital care. It would also be desirable to delineate more specifically geographic areas at higher risk of need for medical care for cancer. Since SEER covers only 10 areas of the United States and only a small number of additional incidence reporting systems exist, incidence data must be supplemented by mortality data to understand better the geographic distribution. In doing so, however, one must be sensitive to the limitations of mortality rates as measures of occurrence of cancer.

Finally, it should be possible to link some simple medical care data directly with incidence data by including in the SEER dataset, for example, date of admission and date of discharge for at least the first period of hospitalization. A more complex procedure would involve collecting data on length of subsequent hospitalizations through the ongoing followup system. This might be attempted at least on a pilot basis to assess its feasibility. Meanwhile, the hospital discharge data from a system such as the National Hospital Discharge Survey is useful.

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Epidemiology and Health Service Resource Allocation Policy for Alcohol, Drug Abuse, and Mental Disorders

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The paper is based on Dr. Regier's presentation at the Second Binational Symposium: United States-Israel, held in Bethesda, Md., October 17-19, 1983.

Synopsis

Data from the NIMH Epidemiologic Catchment Area (ECA) Study in Baltimore, Md., are used to illustrate the association between alcohol, drug abuse, and mental disorder diagnoses with health service use. A probability sample of 3,481 adult (age 18 and over) residents of a geographically defined Baltimore City population of 175,000 was found to have a 23.4 per 100 population, 6-month prevalence of 13 specific alcohol, drug, and mental disorders. Of this population, 7.1 percent sought outpatient mental health treatment from both general

medical physicians and mental health specialists in a 6-month period. The presence of a mental disorder diagnosis increased the average number of visits to all health providers from 1.91 to 4.06 during the same 6-month period.

Although the presence of a mental disorder diagnosis clearly increased the probability of using both general medical and mental health services, only 15.6 percent of the persons with a mental disorder sought any mental health treatment during this 6-month timeframe—leaving 84 percent of those with mental disorders not seeking any outpatient treatment during the same period. The addition of a measure of high symptomatology (a score of 4 or more on the General Health Questionnaire) increased the percentage of persons with mental disorder using services to 30.5 percent. When a measure of disability was added to the diagnosis and the high symptom level score, 54.7 percent of the population could be predicted to use some mental health service.

These data demonstrate the necessity of having additional patient assessment measures with a diagnosis to predict probable service use. However, even in the most comprehensive multidimensional model, more research is required to explore the phenomena of presumed unmet need—the 45 percent of those with a diagnosis, disability, and high symptoms who do not use services.

Hence, epidemiologists who wish to participate in setting policy for resource allocation must join with their colleagues in economics, sociology, and health services research to identify all factors in addition to disease states that either predispose population groups to use services or represent additional resource allocation needs.